

HB101
TESTIMONY

Dr. Darrell J. Micken

1- 17-2007

PROPONENT

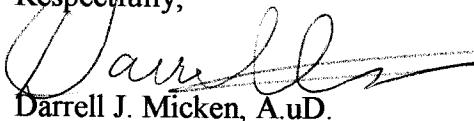
I came into the audiology profession in 1967. At that time there were only 2 organizations which regularly tested children in Montana. These were the University of Montana, Department of Communication Disorders and the Montana Health Department. At that time hearing impaired children, with even moderate hearing losses, were typically sent to the Montana School for the Deaf and Blind in Great Falls. The expense of educating children in a residential facility is high and the emotional impact of removing a child from his/her family and friends is enormous. The children were usually not fit with hearing aids, they were mostly taught and communicated using sign language, and their lives became mostly consigned to the "deaf community"

In the early 70s an effort began to "main-stream" these children in the public schools. Children with moderate and even severe hearing losses were fit with hearing aids and were placed in the public schools in their own communities. Many of these young people have now gone on to become public speakers, teachers, architects, engineers, and business owners in our communities. This change has only been accomplished by early identification and fitting of hearing devices, and a significant effort by their parents and their teachers. And, if a child is to develop normal language skills, they must have proper amplification at the earliest possible age.

The cost of hearing aids is most often covered by the parents, some of whom have 2 or 3 hearing impaired children. The average cost of hearing aids is presently between \$1500 and \$2000 each. Most children require 2 hearing aids, since binaural hearing is necessary, where possible, for information processing. The average life expectancy of hearing aids is between 3 and 7 years. This means that for a single child, the cost of hearing aids, with an average life span of 5 years per hearing aid, will be from \$12,000 and \$16,000. That can double or triple with hearing impaired siblings. At this time there are very few resources to help defray this cost for the parents, other than a few philanthropic organizations. In addition, the schools are not funded to assist in hearing aid purchases. As a consequence, there are still children in our state who go without adequate amplification.

Parental financial assistance is greatly needed to help Montana adequately educate our hearing impaired children

Respectfully,



Darrell J. Micken, A.u.D.

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January 14, 2007

Dear Montana Legislature,

This letter is to urge you to vote to require insurance companies to provide coverage for all medically necessary hearing devices. This would include:

- * Hearing aids and their necessary accessories**
- * Cochlear implants**
- * Cochlear implant processors and their necessary accessories**
- * The necessary doctor visits to fit the equipment and provide necessary adjustments to the equipment and its settings.**

I am the mother of 4 incredible children: Madison 10, Maxwell 8, Milo 5 and Maggie 3. I'd love to tell you in detail about each of them, but I will resist and stay focused on the topic of this letter, Milo.

Milo was born on that infamous day 9-11-01. He was also born with neuro-sensory deafness - we suspect. I say it that way because the staff was not entirely thorough with their testing. It was a troubling day, but Milo was a bright spot. Long story short, after 18 months of halfhearted testing and realizing that he was not producing language, we had an ABR done and discovered that he was in fact profoundly deaf. Milo is a very smart boy and was very good at masking his profound loss which made early detection difficult, but has also made his habilitation a great success.

When he was diagnosed, I was pregnant with our 4th child and devastated. We started signing and tried hearing aids. We quickly found that our insurance would not cover hearing aids or the audiologists or otolaryngologist. Since we were determining whether or not hearing aids would even benefit our son, we were given the option of renting them. That was a great relief; however, the bad news was that Milo did not gain enough from the hearing aids to acquire language. It became clear that a cochlear implant was the best decision.

A cochlear implant involves a surgery where the surgeon inserts an electrode array down into the cochlea which artificially stimulates it. An electric impulse is produced which then travels down the auditory nerve to the brain where the sound is then interpreted. The recipient wears an external processor which is much like a large hearing aid. The internal equipment is permanent but the external equipment requires batteries, cords, magnets, covers, and like any piece of technology, it can

malfunction, wear out or need to be upgraded. As you can imagine this kind of equipment is very expensive and not available at your local Wal-mart.

Being a family of faith, we felt very "led" to have the surgery. Finding out that your child is going to be having surgery is troubling enough, but add to it, that **our insurance would not cover the procedure**, and well, it was a tremendous shock. My husband, Rob, and I have always tried to live within our means and prepare for the unexpected. That is why we had insurance for all those years. We felt completely betrayed and frantic. Time was not on our side. I spent many, many hours on the phone, at the computer and talking to professionals trying to come up with any kind of financial solution. Now, we have always been able to pay our bills, but like most families with 4 children, we didn't have \$60,000 laying around the house. Our surgery was set for August 21st, Milo would turn 2 on September 11th and the baby was due mid-September.

We jumped through all the hoops of appealing to the insurance company. We wrote letters, sent photos, pleading, begging for them to finance our son's very necessary surgery. It fell on deaf ears. . . Pun intended. Can you imagine our frustration? Paying for insurance for years upon years, trying to be responsible parents, and then when we finally turn to them during the most heartbreaking time in our lives, they turn their backs on us.

We began searching for an alternate source for financing even a portion of the operation. We tried Deaf and Hard of Hearing organizations, Service clubs like the Lions, The State of Montana, and the list goes on. When we exhausted all of our resources, we turned to Colorado Neurological Institute (CNI). I worked with Allison Biever who was an absolute Godsend. Let me explain.

I first spoke with Allison on a Friday. She said that they make their donation decisions quarterly and that their next meeting would be in September. I explained that our surgery was the up coming Thursday and that we were going through with it because Milo could not afford to wait. She said that we were exactly the kind of family that they endeavor to help, and she was impressed with our willingness to go through with it no matter what. She made few phone calls and sent some faxes. After a very long weekend of waiting, she called me back. She said that we needed 3 "yes" votes and she had 2 for us. The third was a woman who was in touch with our insurance making sure that we had exhausted every avenue with them. On Tuesday, we had 3 yes's and she overnight shipped the device to the hospital; they received it on Wednesday; Milo went in for surgery Thursday morning at 8:00 a.m. ! See what I mean - a Godsend. God may not be early, but He is never late.

We paid for the hospital, surgeon and anesthesiologist out of pocket. Now remember, you don't just turn it on and "presto! He's fixed!" Not at all. It takes years of determining whether or not the signal is accurate because everyone's cochlea is differently disabled. Compound it by the fact that the patient often doesn't know what "normal" sounds like. Many cannot articulate what is better or

worse because their language skills are so limited. The computer program inside the external processor must be changed and fine tuned over several years as the recipient becomes more and more capable of providing information to the audiologist. The audiologist can then continue making adjustments to the program, or "map", eventually creating a "fingerprint" of sound for each recipient. Moreover, it takes years of training the brain to hear, speech therapy, mapping sessions, working with the equipment, and this all takes time, energy and money.

The surgery was a success and Milo rebounded quickly. It took some time for him to adjust, but relatively soon he was really enjoying sound. He began taking ownership of his equipment and learning how and when to tell me "battery die". Even now, he is the one who gets it out of the drier, puts the battery in and brings it to one of us to turn on. He is not self-conscious or ashamed of his equipment, in fact he is very proud of his processor especially of his new Freedom. He shows it off to everyone, and loves dressing it up with stickers. The new processor is about \$7000.00, (all out of pocket) and we'd been saving for it for a very long time. He was so excited to get it because he had slept with an advertisement for it for several weeks. He would hug it and sing, "Happy Birthday to Milo. . ." We had made a promise to each other and to Milo that we would always keep-up on any advancements - how could we ever deny him that?

We have worked so hard getting him to his current level. Auditory training, sign supported speech, working daily with his teacher of the deaf, special-Ed preschool, doing all kinds of crazy games and activities at home, you name it we've done it. We've agonized over IEPs, learned to sign, networked with other parents and cochlear implant recipients, educated our families, friends, classmates and anyone else who will lend an ear. Recently, we even started flying to Denver for mapping appointments because our surgeon's support staff was producing inferior maps, and we were just not willing to accept substandard care for our son - it's just too important. At times, it does overwhelm us, but the payoff has been enormous. Having access to my little boy's mind is finally happening. He can finally say, "I love you." Or "Mommy, dream scare me." We have waited 5 long years for that.

Now we are trying to give Milo an implant in his right ear. At first, it was a little funny to us that they only did one ear, but we did understand that it was very expensive and that it was a good idea to "save" the other ear for future technology. Now, however, we have done a lot of very dry reading, talking to professionals and asking Milo if he wanted another "ear". We know of other kids who have been recently bilaterally implanted and they are doing really well. Rob and I are not the kind of parents who jump on the bandwagon especially when it comes to our children. We wanted to know about that future technology, and was it going to be available to Milo in a timely manner. We even saved Maggie's cord blood with the hopes of using those stem cells in Milo's cochlea - hey, it was worth a shot. We found that at the earliest, something may be available in about 10 years. Milo would be 15, and we just believe that he needs to receive the most benefit right now.

At first, the thought of Bilateral implantation seemed extravagant, almost like plastic surgery. Is having two just being greedy, or overkill, a luxury even? Well, like I said, I started reading anything I could find on the subject. I never thought I'd need to know about binaural redundancy, signal-to-noise ratio, squelch, head shadow effect, cortical auditory evoked potentials, etc. I found that the brain wants to hear with two ears. The biggest piece is that of the brain being able to better distinguish phonemes. Milo needs every advantage in that area that we can give him. Also, as a mom, the research that I found about how bilateral implantation dramatically supports the social development of the child, is very compelling. Finally, the research clearly supports early bilateral implantation over "saving" the other ear.

Our surgeon gave us very specific information on future technologies and how his implant could be upgraded or modified in the future in an effort to take advantage of new treatments. Our teacher of the deaf was also very helpful in answering our questions concerning habilitation of the second ear. We also have from time to time asked Milo himself. At first, I think he was rather surprised to learn that he didn't fully hear and that it was possible to have more. We used one of the special Cochlear coloring books to help him understand that it is more than just a traditional doctor visit. His language skills are limited, but I do think he understood to a degree, and then later he sat and studied that coloring book for quite some time. Later, he still said that he wanted "2". On a few unprovoked occasions, he has asked for another one and just recently, he told Dr. Von Doersten (our surgeon) that he wanted another one. It is really comforting to know that this time he has a say in it and is okay with it.

So, we are ready to take this big step and once again our new insurance will not pay. Cochlear implants are not covered. We exhausted our resources last time even CNI and of course they don't consider bilateral implants at all. We are committed to the surgery even if we have to go into debt to do it. My fear is that with such a huge bill hanging over our head, will we be able to pay for our portion of his habilitation? Flying to Denver gets very expensive very fast. Clearly, with a new implant he will have to have significant speech therapy and we will be responsible for the cost of that. Also, there is the equipment issue. His processor is very expensive to purchase and maintain.

You as law makers have the great privilege of righting wrongs. In this great country, it is wrong that families have to go to extreme lengths to provide their children with the medical care they need or go without. The Insurance vs. Hospital vs. Patient premiums spiral is out of control - we can all agree on that, right? And it needs to be resolved. We can do it with small steps. The first, is requiring insurance to pay properly and to better detect and prosecute fraud otherwise people will continue to lose faith in insurance companies and to drop their policies. We families cannot continue to pay exorbitant premiums and then pay everything out of pocket. There will be less overall revenues for the insurance companies to draw from and they will either raise premiums, drop coverage or both. Hospitals still must provide health care, but who will pay? Our health care will suffer and therefore, so

will the patients. It has to start somewhere and YOU have the authority and the trust of your constituents to create a solution.

As to this particular law, we would never ask the State to provide all health care to our families - that's ridiculous, but let's be reasonable. Most insurance companies cover prosthetic devices. A cochlear implant is by definition a prothesis. It is common for insurance to provide wheelchairs; why not hearing devices? My child has a disability, and we struggle with it daily. Doesn't he deserve to have necessary equipment provided for him, especially when we pay outrageous premiums?

PLEASE VOTE IN FAVOR OF REQUIRING INSURANCE COMPANIES TO PAY FOR NOT JUST HEARING AIDS BUT ALL MEDICALLY NECESSARY HEARING DEVICES.

Thank you!

Sincerely,



Rob and Nancy Steiner

